



A Publication of the Hawai'i Department of Health Genetics Program

We are pleased to announce that a collaborative effort of the Department of Health, Hawai'i Medical Services Association, Kapi'o'lani Medical Center for Women and Children, Queen's Medical Center, and the University of Hawai'i John A. Burns School of Medicine has resulted in the creation of **Hawai'i Community Genetics**.

Hawai'i Community Genetics

Hawai'i Community Genetics has contracted with the Stanford School of Medicine to provide clinical genetics services and educational activities in collaboration with local genetics professionals and health care providers. As part of our contract with the Stanford School of Medicine, we will be expanding local genetics services and recruiting a full-time pediatric geneticist to be in Hawai'i. The Stanford geneticists will also provide genetics education to medical students, residents, and health care providers.

The insert in this newsletter provides more information about the services offered by Hawai'i Community Genetics, including contact information for patient referrals.

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California Ends Expanded Newborn Screening Using Tandem Mass Spectrometry (MS/MS) Project

As reported by the California Genetics Disease Branch:

"At this time, the one-time funding for the MS/MS Pilot Project has been exhausted. The Newborn Screening (NBS) Program will accept specimens with parental consent for MS/MS Screening that have been collected on or before Friday, June 13, 2003. After June 13, 2003 testing will not be available through the California Program."

The discontinuation of the California Research Project **will not** impact the Hawai'i Tandem Mass Spectrometry Project at Kapi'o'lani Medical Center for Women and Children, which will continue until August 31, 2003. Our regularly contracted newborn screening laboratory, the Oregon State Public Health Laboratory (OSPHL), has agreed to step in and provide the laboratory services for our research project. ***Beginning September 1, 2003, the Expanded Newborn Screening will become part of the statewide mandatory program and the laboratory services will continue to be provided by the OSPHL.*** Please call our Newborn Screening Metabolic Coordinator, Christine Matsumoto, at 733-9069 if you have any questions.

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Issue 3
June, 2003**

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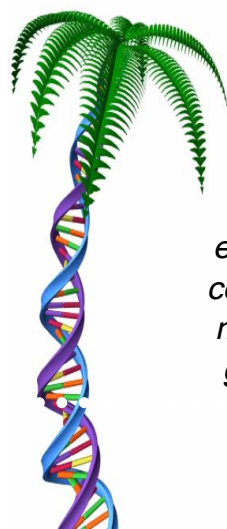
A Big Welcome
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Insert:
Hawai'i
Community Genetics
&
Newborn Screening
Education for Prenatal
Care Providers



**Hawai'i Department
of Health**
Children with Special
Health Needs Branch

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www.hawaiigenetics.org



Highlights of DNA Month!!

April 25th, 2003 marked 50 years since the discovery of the double helix structure of DNA was published. DNA is the marvel of a molecule that encodes much of who we are. This 50th anniversary was celebrated across the country and beyond, in honor of Drs. Watson & Crick and other scientists who made this dynamite discovery, and also to celebrate the impact of DNA and genetics on each and everyone's life.

The Hawai'i Genetics Program planned and hosted several events in order to have Hawai'i celebrating during DNA Month!

Hawai'i Science Teachers' Association (HaSTA) Conference Punahou School

April 12th, 2003

The Hawai'i Genetics Program had the opportunity to be a part of the semi-annual Hawai'i Science Teachers' Association (HaSTA) conference, which took place on April 12th, 2003. HaSTA is an organization open to all public and private science teachers across the State of Hawai'i. We had an opportunity to interact with many teachers, and a chance to inform them about the State Genetics Program.

Teachers in Hawai'i are invited to contact the Hawai'i Genetics Program if they are interested in having genetics professionals speak to their students. In addition, our program is working to develop resources for teachers to facilitate bringing genetics into the classroom. The Speakers Request Forms and other resources for teachers are available on our website. Surveys that teachers completed at the conference will aid us in our efforts to make the "Genetics Resource Kits" the most appropriate and useful for Hawai'i's valued teachers. If you are a teacher and would like to obtain more information or would like to be involved in the development of our resource kits, please contact Allison at allison@hawaiiigenetics.org.

Genetics & Public Health Seminar Series University of Hawai'i Manoa

April 1st, 8th, 22nd, 29th, 2003

The Hawai'i Genetics Program and the University of Hawai'i's Department of Public Health Sciences & Epidemiology jointly sponsored a series of four free seminars during DNA month. Each seminar began with a presentation by a genetics or legislative expert, and attendees were then encouraged to discuss ethical, financial, social and legal issues related to the topic. Topics included: Genetics and Public Health; Genetic Screening From Newborns to Convicts; Genetic Discrimination; and Genetics and the Government. Although the number of seminar participants was small, the discussion was large, lively, insightful, and thought-provoking. We hope to be able to offer similar opportunities in the future.

Dr. Eugene Hoyme presenting at the Genetics for Your Practice Conference



Allison Taylor (left) and Lianne Hasegawa at the HaSTA conference



For more
information please visit
www.hawaiiigenetics.org

U.H. Courtyard during DNA day



A Month of Celebration, Discovery and Success!!!

Genetics for Your Practice Conference Hawai'i Prince Hotel - Waikiki

April 14th & 15th, 2003

The Genetics for Your Practice Conference was organized and run by the Hawai'i Genetics Program. The conference took place over the course of two days, with the first day being targeted towards nurses and allied health professionals and the second day towards physicians. The conference was well-attended, with over 160 participants from O'ahu, Hawai'i, Maui, Kaua'i and Moloka'i.

The conference covered a wide array of topics, including the genetics of several common diseases, genetics resources, and genetics projects occurring in Hawai'i. We were fortunate to have several well-respected and highly recommended speakers join us from the mainland. The conference was a wonderful learning opportunity, and feedback and comments were overwhelmingly positive, including several individuals expressing that it was the best conference they've ever attended! Conference materials will be available on our website at the beginning of July.

We're looking forward to upcoming genetics conferences, and will keep you updated through future issues of Gene News!

Many gather at the Genetics booth.



UH University of Hawai'i Manoa - Campus Center Courtyard DNA Day!!

April 23rd, 2003

The Hawai'i Genetics Program sponsored a fun and interactive "DNA Day" to raise awareness of genetics, related career opportunities, and our program. Clear Channel Radio Stations Star 101.9, Island Rhythms 98.5 and I-94 added fun and excitement to the day, and increased attendance by playing radio ads during the days leading up to DNA Day. The day included prizes, games, a climbing wall, and information from the Hawaii Genetics Program.

Several hundred attended the event, including college students, faculty and staff, high school students, and visitors to the university. 220 individuals (mostly college students) completed a short survey, which asked their college level, major, previous genetics education, and opinions on genetic testing. When asked about testing for a hypothetical condition that would cause loss of mental and physical skills in the next 10 years, 53.2% reported that they would choose to have testing soon to see if they carry the gene, and 19.1% reported they would want testing at a later date. When the question was asked regarding a hypothetical condition that would onset in 30-40 years, 39.5% reported that they would want testing soon, and 32.7% reported they would want it at a later date. A more detailed overview of the survey results will be posted on our website.

Hawaii Department of Health
Genetics Program
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A Big Welcome...

The Genetics Program welcomes a new genetic counselor!! **Christine Lee** joins our staff as a summer intern. Christine recently received her masters degree in Human Genetics and Genetic Counseling from Sarah Lawrence College. Please join us in welcoming Christine to Hawai'i.



*Christine Lee is welcomed by
Chris Matsumoto (left).*

And A Big Aloha...



*From Left to right, Sharon Hirose, Lianne Hasegawa,
Nicole Sameit with Breanna, Pauline Mui, Allison Taylor,
and Sylvia Au*

The Genetics Program sends Congratulations and Aloha to **Nicole Sameit**. Nicole has been with the program since we started our new State Genetics Plan assessments in 2000. Nicole and her husband, Paul, recently became the proud parents of Breanna. Breanna is a happy, healthy and gorgeous little girl. We want to thank Nicole for all her hard work over the past three years and wish her all the best for the future.